



Portsmouth Parent Voice (PPV)  
Run by parents for parents of children and  
young people with additional needs or  
disability

# **IMPACTING ON YOU**

## **Newsletter**

March 2018

Information, advice and support for parents/carers of children and  
young people (0-25) with special needs and disability



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Hi Everyone!

Welcome to the latest edition of Impacting on you.

We had a busy month with our **annual event** taking place (see pictures on **page 15**) and lots of meetings to attend both locally and regionally. Our parent reps are very busy working on so many work strands, they are to be commended for their commitments and efforts. Capacity is always an issue for all parent carer forums nationally, so if you would like to get involved, do get in touch with us 😊

We have several **surveys and consultations** taking place at the moment looking at the continence service and CAMHS services. Please do complete and share these as we need the evidence to understand why things are not working as effectively as they should in order to change services for the better (see **page 17**)

We are also delighted that “In Control” Partners in Planning are running their **amazing FREE training** in Portsmouth over the next few weeks to enable parent carers, young people and professionals to work together to improve services locally. Not to be missed (more on **page 7**).

Finally, a quick reminder that we will get in touch with you in **April** regarding our **newsletter mailing list** in order to comply with the General Data Protection Regulation (GDPR). You will find more information on **page 6**.

Best wishes

Barbara and the Team

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# What's On?

## Events and workshops coming up soon

Are you a parent or carer of a child or young person with additional needs and disability and living in Portsmouth?

We run various coffee mornings, events and training sessions in partnership with several voluntary groups ( **Autism Hampshire, Contact**) and statutory agencies (such as **CAMHS**- Child and Adolescent Mental Health Services)

Event	Date and Time	Venue
<b>Healthier Together Website</b>  Information parent carers need to have their questions answered on the website More information on page 6	<b>Tuesday 20<sup>th</sup> March</b>  <b>10 am to 2 pm</b>	<b>The Frank Sorrell Centre</b> Prince Albert Road Southsea PO4 9HR
<b>PPV Coffee Morning</b>  Support and Information session	<b>Tuesday 24<sup>th</sup> April</b>  <b>10 am to 12 pm</b>	<b>The Frank Sorrell Centre</b> Prince Albert Road Southsea PO4 9HR

# Information Update

From **May 2018**, organisations will be required to request consent from anyone on their mailing list or database. Even as a small charity, we are required to comply with this legislation.

The **General Data Protection Regulation** (GDPR) expands the rights of individuals to control how their personal information is collected and processed, and places a range of new obligations on organisations to be more accountable for data protection.

You can find more information here: <https://www.itgovernance.co.uk/data-protection-dpa-and-eu-data-protection-regulation>

Over the next couple of months, we will send you email reminders of this change. Once we are ready to send you a request for your consent, we will only be able to do this **once**. If we do not hear back from you, your name will be deleted from our mailing list.

From **April 2018**, our newsletter will move to Mail Chimp and this is when we will send you a request to confirm whether you wish to remain on our mailing list.

You will still be able to download our newsletter from our website.

You do not need to do anything now but do keep a close eye on your email folders for further communication.

Thank you



# Healthier Together Website Information Event

The Frank Sorrell Centre  
Prince Albert Road  
Southsea PO4 9HR

Tuesday 20th March  
9.30 am – 1.15 pm

*What information do you  
want to see on a website?*

*Where do I find support and resources?*



**Portsmouth Parent Voice** would like you to come and share your views and expertise about information on health related matter.

Refreshments and lunch will be provided.

**To book: Eventbrite**

<https://www.eventbrite.co.uk/e/healthier-together-website-consultation-tickets-42897739293>

[ppvadmin@p-d-f.org.uk](mailto:ppvadmin@p-d-f.org.uk) or call 07825 185 608 for more information



# In Control FREE Training

The first workshop of a series of 6 took place on Saturday 24<sup>th</sup> February.

Delivered by In Control, the morning session covered the **journey about special needs and disabilities through history** and how difficult it is to change attitudes. Lynne explained how parent carers, children and young people can **influence decision makers** as a collective voice and the training delivered by In Control is to do just that!

In the afternoon, Steve McGuinness talked about his experience of **growing up with autism**, how he found his coping strategies and how he is trying to change local authorities' behaviour through his consultancy work.

Everyone learned a great deal from all speakers involved and we all look forward to the next instalment.

Our favourite line from Steve: "I am told by that I have a communication disorder by a local authority that can't communicate with me!".

In control are a national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution.

In control are hosting a series of free workshops in Portsmouth. These workshops will help parents, children and young people to understand their rights and how to make change happen locally. Most sessions include guest speakers who can talk about their own personal experiences either as a person with life experience of living with a disability or as a parent carer.

All sessions will run at the Frank Sorrell Centre, Prince Albert road, Southsea, PO4 9HR. Sessions will run from 9:30 am for refreshments with a prompt 10 am start until 3:30 pm.

It is recommended that you attend all workshops but we do understand that it might not always be possible. **Do select the date required when booking**



## **Forthcoming workshops:**

### **Friday 9th March**

How to get a job, live independently and for be in control using your skills.

*Speakers:*

Joanne Morgan – Gig Buddies

“My name is Jo Morgan, I have lived and worked in Portsmouth and surrounding areas for the last 18 years predominantly in Finance and most recently for the last 9 years as a fully qualified Chartered Management Accountant in the manufacturing sector where I was responsible for all aspects of Financial Management including supervision of a team of 6 with Finance and HR/Payroll duties. My background in Finance has given me strong organisational skills and the ability to work logically and methodically and to tight deadlines. I am also a parent volunteer with Portsmouth Down Syndrome Association as Events Team Leader looking after a group of 5 parent volunteers and between us we manage the social events calendar.

I am a wife and mother to two small children aged 10 months and 2.5 years. My eldest child has Down Syndrome. My role at Gig Buddies is perfectly suited to enable me to bring together my skills in management and events planning with my role as a parent to a child with Special Educational Needs and my aspirations for her to have as many opportunities in adulthood as we all have.”

### **Saturday 10th March**

Ways of **planning** for the future, **real life stories** of how being in control has supported people.

*Speakers:*

**Andy Walker:**

Hear Andy's story of success and tragedy by overcoming the odds living with a high-level spinal cord injury. Andy will inspire and motivate you and your

students to overcome any barrier, embrace challenges and go on to achieve your dreams in life!

<https://www.schoolspeakers.co.uk/speaker-listings/andy-walker>

**Lisa Watchorn:** Proud mum, carer, disability activist passionate about real inclusion and self directed support, choice and control.

## **Friday 23rd March**

The benefits of person centred planning, how to **make it work for you** and your family.

*Speakers:*

### **Kath Bromfield:**

"I am a mother to four children and am a very proud Mancunian. My background is in education, but as a parent/carers I felt unsure of the way forward until I went on a parent leadership course with Partners in Policy making. This really challenged my thinking and I then became Chair of Rochdale Parent Carers' Voice. I am passionate about the inclusion of people with disabilities in all aspects of life, and an active trainer as well as expert by experience and person centred planner. I have delivered training to forums nationally and work closely with my own regions NWTDT/Pathways to ensure inclusion happens in all areas of our society, particularly for those in or at risk of hospital settings."

<http://www.nnpcof.org.uk/kath-bromfield/>

### **Will Case:**

William has been an Independent Disability Consultant / Self-Advocate for 8 years. He first became a Disability Consultant after undertaking a national leadership course in disability equality and social justice, called Partners in Policy Making. William has gone on to work alongside some of the key organisations in the disability field such as In Control Partnerships, MENCAP, The Council For Disabled Children as a CDC young ambassador and Alliance For Inclusive Education as a researcher. He also contributed towards some of the UK government national policies on disability issues, such as the Family and Children's Act of 2014 and the Every

Disabled Child Matters review into the Personal Independence Payments for young people. William now consults with many charities, organisations and local government bodies around the country.

In 2011 William was one of 100 people in the UK to receive a fellowship grant from the Winston Churchill Memorial Trust. William was actually the first person with cerebral palsy to receive a fellowship grant in the UK. His research looked into Best Practice of Disability in the USA, where he spoke to both people who run the services and the recipients. William also met some of the Self Advocacy groups who aim to ensure that the self-advocacy movement is still active in the USA.

William is a progressive thinker and proactive in enacting social equality and justice. He has a deep commitment to inclusion rising from his own life experience.

<http://www.naidex.co.uk/speakers/william-case-/>

## **Saturday 24th March**

### **How to be part of society and your local community.**

*Speaker*

#### ***Joe Whittaker***

Joe Whittaker has been actively promoting Inclusive Education across all sectors of education since he himself was expelled from school in the 1960's.

It is his strongly held view that individuals do not have learning difficulties/disabilities but Schools Colleges and Universities do! We need to put our energies into working to overcome difficulties within our systems, by making them fully inclusive and fully accessible.

Joe retired from 35 years as a teacher with 25 years in Teacher Education encouraging teachers to start by welcoming their students into the learning process.

Joe is now Chairperson of The Alliance for Inclusive Education, campaigning for an end to segregated education. He has travelled widely and connected

with people in many countries who express and experience the negative consequences from segregated and deficit approaches to learning.

Currently Joe is working with a group of very assertive individuals, who call themselves Quiet Riot, they do not use speech to communicate, but have a great deal to communicate about the world can be improved..

### **Friday 20th April**

Focusing on **raising local issues** to senior managers. A chance to talk to local people who help decide what services exist in Portsmouth.

### **Saturday 21st April**

Managing change and **making things happen** locally. How you can make a difference.

This training is **FREE** and is open to parent carers, children and young people and professionals working in the field of special needs and disabilities.

Lunch and refreshments are provided but do let us know if you have any dietary requirements.

The venue is fully accessible. You are welcome to park in the car park on the day.

For more information, please contact 07712 439 159 or email: [ppvadmin@p-d-f.org.uk](mailto:ppvadmin@p-d-f.org.uk)

**To book**, please go to: <https://www.eventbrite.co.uk/e/in-control-workshop-tickets-43610954539>

# The Portsmouth Local Offer Website



The Portsmouth Local Offer website was launched over 4 years ago and was designed in co-production with Portsmouth City Council (PCC) and Portsmouth Parent Voice (PPV). A group of parent carers still meets monthly to review the information the website contains and to ensure that the resources provided are easily accessible.

A parent representative now meets the officer in charge of the website also on a monthly basis to produce the “You Said, We did” report which you can find on the newsfeed on the left hand side of the front page of the website. We use parent’s feedback to inform us when the information can’t be found, is not worded correctly or out of date which in turn are amended accordingly.

If you use the website as a parent carer, young person or professional, do use the feedback button on the top right hand corner to give your comments not only if you can’t find the information but also if you can’t find a service or support you are looking for as it will help us identify gaps in services. We want to take the website further, not only to give information but also to change the way services are commissioned in the city.


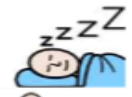






**Go on, have a look! <http://www.portsmouthlocaloffer.org/>**

# CAMHS LD Accessible information Sleep Project

CAMHS-LD Accessible Information Sleep Project



## Information Letter

	The Children and Mental Health Service Learning Disability (CAMHS-LD) team want to <b>improve the information</b> they give to children and families, whilst they are waiting to be seen.
	<b>Sleep</b> is one of the main problems that families want help with.
	We would like to develop <b>on-line self-help resources</b> that are accessible to all.
	The online resources could include: <ol style="list-style-type: none"> <li>1. An information <b>film</b> for families,</li> <li>2. An <b>animation</b> for children,</li> <li>3. Easy Read <b>information sheets</b> and</li> <li>4. <b>Communication resources</b>.</li> </ol>
	We would like to develop these resources in <b>partnership</b> with people who have lived experience.
	If you have had help with <b>sleep</b> from the CAMHS-LD team, we would like to hear from you.
	If you are interested in working with us on this project, please complete the ' <b>I'd like to help</b> ' form.
	This form will be shared with the project lead <b>Clare Mander</b> (Clinical Lead for Accessible Information) who will make contact with you.

If you are interested in this project, please complete the form on our website (<http://www.portsmouthparentvoice.org/news/camhs-ld-accessible-information-sleep-project/>) and email to: [accessibleinfo@solent.nhs.uk](mailto:accessibleinfo@solent.nhs.uk) when completed.

Discount Available  
to parent carers  
on request.



Let's talk  
Makaton

Foundation stage workshop  
Monday 16th April & Tuesday 17th April  
9am until 4pm

The Foundation Workshop is a fun and practical workshop, providing the basic training in Makaton which is recommended for professionals and others who may come into contact with a wide range of Makaton users and who will benefit from a broad knowledge of Makaton

The course will be held at:  
Cosham Masonic Centre  
The Masonic Hall, Cosham  
Portsmouth PO63DD

There is plenty of parking and it's a 10 minute walk from Cosham train station.

The cost will be £150 per person, this will include:

- Workshop manuals
- A recognised Makaton qualification &
- Support from Makaton professionals with years of experience.

Please bring your own lunch there will be tea & coffee provided.

Please contact [positivecommunication@mail.co.uk](mailto:positivecommunication@mail.co.uk) for further information and a booking form.

Book your Makaton foundation course with us and get a 10% discount off the Enhancement course which will run in May/June

# Local Offer Live 2018 in Pictures

Over 40 Exhibitors



Over 180 parent cares and children



Feedback for next year: more school representations and heating!!!



## ASD Drop-in Sessions

Do you have a child who has been referred for ASD Neurodevelopmental Assessment with Community Paediatric Service (0-5) or CAMHS (6-19)?  
Do you have questions about challenging or unusual behaviour?  
Are you looking for a support network to connect with?  
Do you have questions about the assessment pathway and what to expect?

CAMHS & CPMS (Community Paediatric Medical Service) have a Liaison & Support Worker ready to give you advice and guidance at a number of rotating drop-in sessions, details below. Please contact Daniel Bevan on 07585960296, or by email [dan.bevan@solent.nhs.uk](mailto:dan.bevan@solent.nhs.uk) for more information or to book a drop-in slot.

Date	Time	Venue
4 January 2018	9.30 - 11.30	Battenburg Child Development Centre Battenburg Avenue, Portsmouth
18 January 2018	9.30 - 11.30	Somerstown Family Hub Omega Street, Southsea
1 February 2018	9.30 - 11.30	Portsmouth CAMHS Falcon House, St James Hospital
15 February 2018	9.30 - 11.30	Paulsgrove Family Hub Cheltenham Road, Paulsgrove
1 March 2018	9.30 - 11.30	Battenburg Child Development Centre Battenburg Avenue, Portsmouth
15 March 2018	9.30 - 11.30	Somerstown Family Hub Omega Street, Southsea
29 March 2018	9.30 - 11.30	Portsmouth CAMHS Falcon House, St James Hospital
12 April 2018	9.30 - 11.30	Paulsgrove Family Hub Cheltenham Road, Paulsgrove



# Your Views and Consultations

## Wellbeing and mental health support- your views and experience.

We would like to find out about parent carers' experiences of services and support in regards to wellbeing, emotional and mental health issues for their children and young people (0 to 18).

Your feedback is so important and will enable us to share this information with commissioners and service providers in order to improve services and identify gaps.

If you have accessed the Community Paediatric Medical Services (**CPMS**), Child and Adolescent Mental Health Services (**CAMHS**) or had an admission to **A&E**, we would value your input. The survey should take between 5 and 10 minutes to complete.

To complete the survey, please follow this link:

<https://www.surveymonkey.co.uk/r/QCH5ZV2>

## U Matter

The U Matter Service was launched in 2017 and we would like to hear your views on the services if you have accessed it whether as a parent or a young person.

You can find more information about the service

here: <http://www.portsmouthlocaloffer.org/local-offer-search/item/357>

And complete the survey here: <https://www.surveymonkey.co.uk/r/WXJ2P25>

## Continence service

Have you used the continence service for your child or your person? What was your experience like? Please complete this short survey to share your views.

<https://www.surveymonkey.co.uk/r/ZJ23XZH>

## You views on the Education, Health and Care Plan (EHCP) Process

We would like to hear about your journey through the assessment process, whether you have transferred from Statement to the new EHCP (Education Health and Care Plan) or if

you have requested an assessment for an EHC Plan. We want to see what is working for parents and what needs more work, so we can take this back to the Local Authority.

We will then work with the Local Authority to share any good practices across all the schools in Portsmouth and look at ways we can improve anything that is not working.

To help us with this, could you take the time to complete the following surveys:

For a new Education, Health and Care Plan

<https://www.surveymonkey.co.uk/r/VNNRL9M>

For a transfer from a statement to a new Education, Health and Care Plan

<https://www.surveymonkey.co.uk/r/VXSGDQ8>

As a thank you, you will receive a £5 Tesco gift card.

### **Carer's Cafe/Information Point - User Questionnaire**

Portsmouth Hospital Trust would like to further support carers in the community as well as those accompanying patients who attend Queen Alexandra Hospital. We would like to hold a monthly Carers Café/ Information Point in the main entrance of the hospital. We would be grateful if you could take a few minutes of your time to let us know what this could look like, by answering the questions below. Your participation is voluntary and all answers will remain confidential.

Please could we have your thoughts by 12th February 2018. Thank you.

<http://www.elesurvey.co.uk/f/614899/b8a5/>

## NEWS IN BRIEF

### Sensory Integration Holidays

We design quality, bespoke inspirational holidays for people on the autism spectrum, their families and friends. Our multidisciplinary specialised team of psychologists, therapists, artists and tourism and hospitality experts will help you customise all aspects of your holiday so as to enjoy the best possible experience. Our inspirational holiday adventures will spark new exciting ways of expression and personal development.

For more information: <http://www.psychagogia.co.uk/>

### National Children's Day UK

**National Children's Day UK (NCDUK)** is all about the importance of a healthy childhood and how we need to protect the rights and freedoms of children in order to ensure that they can grow into happy, healthy adults.

This year National Children's Day UK is taking place on **Sunday 13th May** and people can run any kind of big or small event that they want for the week up to and including the day. From small family outings, to whole school and community events, local authority initiatives, talks, seminars and city-wide celebrations, it's an opportunity for everyone to raise awareness about the things they care about or projects they are running.

#### **An increasingly important national event**

Over the five years since its launch the day has attracted the support of hundreds of organisations throughout the UK. These include: children's centres, nurseries and schools, local authorities, the national Play organisations, The National Trust, The Wild Network, The Football League Trust, Eureka National Children's Museum, The Childhood Trust, the Mental Health associations, Action for Children's Arts, Pip UK, Coram, Pre-school Learning Alliance, Steiner Waldorf Schools Fellowship, Human Values Foundation and many others.

For more information: [sally.grindley@nationalchildrensdayuk.com](mailto:sally.grindley@nationalchildrensdayuk.com) or visit their website: <http://www.nationalchildrensdayuk.com/>

## CAMHS Training Courses

### **Managing Anxiety and Self-Harm**

Anna Walker, Community Nurse Therapist

Melanie Wells, Training and Coordinator Lead

Thursday 22nd March 2018 – 9:00 am – 3:30 pm

Portsmouth Academy for Girls – Education and Learning Centre

Cost £75 per person (includes resource pack, power point and follow up session)

Self-harm is a growing concern in Portsmouth children and young people. This course will equip staff with the skills and confidence to work with young people who are suffering with anxiety or who are self harming.

Many young people who self-harm are using this as a way of managing overwhelming feelings of anxiety or distress, some may feel suicidal. This workshop will enable you to use the self-harm care pathway and equip you with the confidence and strategies to support these young people.

We suggest that managers put forward staff who have the skills and confidence to disseminate this training to their colleagues as this course gives delegates the resources to do so.

Comments from our last training day:-

'This has been excellent training particularly with the resources provided'

'Extremely useful direct tools to use'

'This was excellent training, relevant, rich and expertly delivered'

'Real life examples used'

Although this course is aimed at professionals, parents are welcome to attend.

Please note that unfortunately, no discount is available.

To book your place, please email: [melanie.wells@Solent.nhs.uk](mailto:melanie.wells@Solent.nhs.uk)

## **BRAAIN (Be Ready ADHD ASD Information Network):**

BRAAIN is here to help parents with that have Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) and/or other special educational needs (SEN). When you are not sure where to turn, BRAAIN will give you the information you need! For more information, visit their website at <http://www.braain.co.uk>.

They have a Facebook group for parents to have a space where they feel comfortable to share their struggles, thoughts and feelings. This can be accessed here:

<https://www.facebook.com/groups/adhdandasdttimeout/#> = In addition to this, they know it is important for healthcare professionals to be able to share information and they are keen to help ensure this information reaches parents. So they have set up a group for professionals to share events, activities, clubs and more which BRAAIN can share with their families. This can be accessed here:

<https://www.facebook.com/groups/BRAAINProfessionals/#> = Please be aware they have

a 'No advertising of private care/services' on the group. If you have any questions, email [enquiries@braain.co.uk](mailto:enquiries@braain.co.uk)

## Help for young people and families in Portsmouth

The Early Help and Prevention service in Portsmouth is a new way of doing things – providing extra practical help with families early on, to stop problems getting worse. We talk with families about the things that are most important to them, what might help and what we can do differently to help them. This is how we start working together with the whole family to help get things back on track.

Help is available for families with children aged 0-19.

For more information, please go to : <https://www.portsmouth.gov.uk/ext/learning-and-schools/pre-school/childrens-centres>

## You can keep in touch with us using the following



Website: [www.portsmouthparentvoice.org](http://www.portsmouthparentvoice.org)



Facebook: Like our page Portsmouth Parent Voice



Twitter: You can follow us at @PparentVoice



Email [ppvcoordinator@p-d-f.org.uk](mailto:ppvcoordinator@p-d-f.org.uk)



Phone: 07825 185 608



Instagram: [ppvcoordinator](https://www.instagram.com/ppvcoordinator)



Pinterest: Portsmouth Parent Voice



Write: Portsmouth Parent Voice

The Frank Sorrell Centre, Prince Albert Road, Southsea, PO4 9HR